His Story

July 28, 2014 By Aundaray Guess

Last week I had a somber encounter with a person I have known casually for a few years. For the sake of this post I'll call him Tony. In reality his name doesn't matter as he represents so many who lives with HIV. As a HIV positive person for two decades, he is a member of the group of men and women who have been positive for a large part of their lives. In fact Tony has been positive for twenty something years. So his story speaks to the long-term survivors who are creating new chapters of dialogue. A unique audience in which the spotlight of HIV discussion often fails to illuminate.

Somehow in our conversation we started to talk about medication adherence. I was letting him know, although I wanted to take a 'holiday' (a break from my medication), I knew the risk of it. He looked at me plainly and shared he was no longer on HIV medication.

His reason was sad to hear. He reported it wasn't his choice; he recently became resistant to all available HIV medication, including his own regimen. He described how when taking his medication it would immediately leave his body either by regurgitating it or having extreme diarrhea. His doctors informed him he had no immediate options.

I knew his story as I was once resistant to my own medication and flew solo. None of the drug classes would help me. It was a scary time as it seemed I was on my own. Each month my t-cells were dropping lower and my anxiety was rising higher. What's worse, it was during the flu and cold season when it seemed everyone around me was sneezing or coughing. So it was a careful navigation of avoiding any contagious environments. Not an easy task living in New York City. it was a reminder that HIV doesn't kill but the opportunist infections one gets. So in my case, a simple bug which which before my body could fight, now had no protection.

My resistance came from not adhering to my medication. I took the pills for granted and somehow convinced myself they were only a crutch I could use when needed. So I knew my story, but I didn't want to make the same assumption about Tony. I figured there had to be some option. Alternatives such as participating in studies of upcoming HIV trial medications. This was my life-saver as I was introduced to a study which eventually was approved. A study which opened the door for new medication to help.

Sadly he let me know it didn't matter. He then said two words I sometimes said to myself but never uttered out loud.

"I'm tired"

And in that statement my attempt to persuade him to not give up was shot down. Now I knew his story. As someone who lived with HIV for two decades he was growing tired of the battle. Someone from the outside would think he was tired of taking pills but for those who are HIV positive they know it's more than that. It's sometimes the physical toll your body goes through. Maybe it's the emotional aspect that makes it difficult. And there's always the never ending stigma

which trails you and seems unbeatable. And in Tony's case a new battle we all must face, aging. Only his aging included a disease which accelerated the process. An expedited process which remained unknown on what the full effect of taking HIV medication for a long term does to one organs. He was tired and I understood.

There have been days when I think I've reached my own limits. When I find myself in those alone space. When you have the countless needles injected in your arm, drawing your tainted blood for lab work. When your body starts to give up before you do. And for some, those endless days when potential relationships are cut short when they hear the words, HIV. Luckily for me I had a cheering section of friends and loved ones who kept me motivated. I also had a good life with dreams and goals. I had a reason for life.

I didn't know his story.

In his case his loved ones may have moved on or passed away which resulted in his loneliness. Maybe his reality was accepting the knowledge as you get older you have more acquaintances than friends, true friends. Perhaps his dreams were deferred and now seemed out of reach. Or maybe he reached his goals and felt there were no new roads to discover.

In his tiredness he didn't tell me he wanted to die, but in his voice I heard acceptance if that was the result, then so be it. As if his HIV had taken away his purpose.

It seemed the soft killing of his dreams and hope took out the fight he once had.

Someone who didn't have the disease or someone newly diagnosed, sleeping on clouds of optimism would judge him and tell him to keep fighting. Those who were fresh to the battle and had yet earned their battle scars, could pass incorrect conclusions. Not knowing the miles he has walked.

It made me wonder, as a long term survivor myself, was his story soon going to be mine. Would it be a test of who gives up first, me or my body? What did my future hold as someone living with this disease for almost three decades? And looking at the physical toll these HIV medications causes as we age, what new battles waited and would I be ready?

If the people who love me left one by one and I was now in the golden years of my life, would I still want to keep going or simply raise my hands and tell myself, what comes, come. Would I now be Tony?

He was tired and his story didn't leave for any solutions. I just took comfort in him knowing no matter what decision he made about his life I would be there for him as a friend. Even if it meant the end.

That was my story.

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